



**Long Term Care Coordinating Council
Working Group to Develop a State Plan for Alzheimer's Disease and Related
Disorders**

Full Group Meeting

8:30 – 10:00

Thursday, February 21, 2013

Child and Family (formerly Casey Family Services)

1268 Eddy Street

Providence, RI 02903

AGENDA

I. Call to Order

- a. The meeting was called to order at 8:38 am.

II. Approval of Minutes from December 13, 2012 Meeting

- a. The minutes were approved unanimously.

III. Report Outs from Sub-Groups

- a. Caregivers – The Caregiver and Access subgroups had two joint meetings together to address what services are being coordinated and made available to patients and caregivers alike. A big portion of this work was focused on 211/The POINT. The subgroups hears of many services that could be better coordinated and that many people were not yet aware of. One such program is the respite care – Care Breaks program being managed through the Diocese. The Diocese is doing a respite care assessment which will be available very soon.
- b. Workforce – The group has been conducting a survey to assess the state of existing dementia training and education opportunities. It is having some difficulty penetrating the emergency and urgent care settings as well as physicians, but may come through. Another challenge the group is looking at is how to serve people with dual diagnosis of mental illness and dementia. What training is being offered to the provider community and do we have the proper capacity? Co-location of caregiver care and patient care is another area that needs some attention. The group will like make some recommendations around this piece.
- c. Access – *see* Caregivers report out. The group also heard from Gail Patry, from Healthcentric Advisors, regarding the care transitions work being initiated out of their organization, as well as Director Taylor, who shared levels of funding streams relevant to the Alzheimer's/dementia population.

- d. LTC – This group has spent two meetings hearing from industry leads on best practices in dementia care (assisted living, nursing home, adult day programs and most recently, home care).
- e. Research – The Research Subgroup has focused on recommendations around a yearly research symposium, a way for state-based private researchers to learn more about the data collected by the state, and an online resource to connect families, people living with Alzheimer's, providers and other stakeholders with up-to-date research and best practices information, support group information and other services and support, and to connect potential participants to clinical trials.
- f. Legal – The Legal Subgroup most recently heard from Martha Crippen, a member of the Attorney General's Elder Abuse Unit regarding the challenges they see in prosecuting crimes against vulnerable seniors. There are some serious resource challenges. Additionally, the group is hoping to work with Roger Williams Law School Students, through their Elder Law Society, on some recommendations for DMV rules and regulations around safe driving standards.

IV. **Overview of the Norman Prince Neurosciences Institute - John Robson, PhD** – Associate Director for Medical Research and Clinical Programs at Brown's Institute for Brain Sciences *and* the Administrative Director of the NPNI

- a. Presentation available upon request.

V. **Introduction to Al's Moving Minds**

- a. Anne Mulhall, the Executive Director, shared a short overview of her organization. She originally conceived of the organization after experiencing the disease first-hand with her father. They work to provide respite care with activities the person living with the disease is interested in – whether they were former fisherman, golfer, bowler, singer, etc., the organization organizes two-hour activities for the caregiver to drop their loved one off at. Volunteers are asked to commit to 4 weeks minimum. The activities are free to the participant and they are constantly adding new ones.

VI. **Administrative Items**

- a. Update on most recent Listening Sessions – Progreso Latino *and* Dorcas International Institute
 - i. The final two listening sessions were not attended widely, however, some important takeaways were gained; very few services are offered with Spanish, Portuguese or other language competency. One major challenge is to identify the extent of interest/need and help build the case for more culturally competent, skilled language programming to exist.

- ii. The Co-chairs are interested in trying to leverage radio communication to continue outreach.
 - iii. An extended online comment period should also be utilized in tandem with radio/print outreach.
- b. Remaining Work – Subgroup calendar, draft circulation, public comment period, final State Plan
 - i. There are two additional Full Group meetings scheduled; April 4th and June 6th.
 - ii. A public comment period will likely be held in late May/early June.
 - iii. The final draft will be discussed at the June 6th meeting and presented to the General Assembly shortly thereafter.

VII. Public Comment

- a. There was no public comment.

VIII. Adjourn

- a. The meeting was adjourned at 10 am.

Questions?

Please Contact:

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Meeting	Date	Location
Caregivers	March 19 th at 11 am April 16 th at 11 am	Diocese of Providence
Workforce	TBD	Healthcentric Advisors
Access	March 5 th at 11 am April 5 th at 11 am	RICCMHO
LTC	March 20 th at 9 am April 17 th at 9 am	Elmhurst Extended Care
Research	March 12 th at 4:30	CORO (West) Suite 304-A

	April 25th at 4:30	
Legal	March 28 th at 8:30 am April 18 th at 8:30 am	Location TBD
<i>Next Full Group</i>	April 4 th June 6th	Casey Family Services <i>unless otherwise noted in announcement.</i>

**This meeting information is tentative.* Please refer to email notices from Lauren Lapolla and/or Lindsay McAllister for the most up-to-date meeting information.